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Lupus and Nursing Care: Current Knowledge and Future Directions

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Abstract

Background: Systemic lupus erythematosus (SLE) is a complex autoimmune disorder with diverse clinical manifestations and significant impacts on patients' physical and psychosocial well-being. Given their pivotal role in patient care, nurses must possess adequate knowledge and skills to manage SLE effectively. ***Objective:*** To assess the knowledge and practical approaches of nurses regarding SLE in order to identify educational needs and improve patient care. ***Methods:*** A descriptive, cross-sectional quantitative study was conducted between December 2024 and February 2025 in two university hospitals in Sousse, Tunisia. An anonymous, pre-tested 29-item questionnaire assessed nurses' demographics, knowledge of SLE, and related practices. Nurses from internal medicine, dermatology, rheumatology, and nephrology departments with at least six months of experience were included. ***Results:*** Seventy nurses participated, predominantly female (77.1%) with a mean age of 35.77 years. Dermatology was the most represented department (30%), followed by nephrology (24.3%). While 92.9% identified SLE as an autoimmune disease, only a minority recognized its chronic nature. Knowledge of affected demographics and treatments was moderate, though misconceptions about immunosuppressive therapy were common. Preventive strategies such as sun protection and nutritional guidance were poorly known. Nearly half the participants emphasized the nurse's role in patient communication and psychosocial support, and fewer cited stress management or therapeutic education as strategies for managing flares. ***Conclusion:*** Despite general awareness of SLE, significant knowledge gaps persist among nurses, particularly regarding treatment mechanisms and preventive care. These findings underscore the need for targeted training programs to enhance nursing competencies and improve the multidisciplinary management of SLE.

Keywords: systemic lupus erythematosus, nursing knowledge, autoimmune diseases, patient care, therapeutic education, nurse training

1. Introduction

Systemic lupus erythematosus (SLE) is a complex autoimmune disease with multisystem involvement that may lead to life-threatening or disabling complications (Tsokos GC., 2011). Its prevalence ranges from 20 to 150 cases per 100,000 people, depending on the region (Mak A & Kow NY., 2014), and it primarily affects women of childbearing age. Clinical manifestations vary widely, from mild symptoms like arthritis and skin rash to severe complications such as lupus nephritis and neuropsychiatric disorders (Ruiz-Irastorza G, Danza A & Khamashta M., 2010). Environmental triggers such as UV exposure, infections, and certain drugs contribute to SLE onset and flares, underscoring its complex pathogenesis (Danchenko N, Satia JA & Anthony MS., 2006). Beyond physical symptoms, SLE affects patients' psychosocial well-being and socioeconomic status (Ruiz-Irastorza G,

Danza A & Khamashta M., 2010; Lupus Foundation of America, 2020). Nurses play a vital role in managing SLE, yet knowledge gaps may hinder care quality (Pons-Estel GJ, Ugarte-Gil MF & Alarcón GS., 2010). This study evaluates nurses' knowledge and practices to identify training needs and improve SLE care.

2. Methodology

A descriptive, cross-sectional quantitative study was conducted from December 2024 to February 2025 using an anonymous, pre-tested questionnaire to assess nurses' knowledge and practices regarding systemic lupus erythematosus (SLE). The study involved nurses from internal medicine, dermatology, rheumatology, and nephrology departments at two university hospitals in Sousse. Eligible participants had at least 6 months of experience and gave informed consent. The 29-item questionnaire covered demographics, SLE-related knowledge, and nursing practices.

3. Results

The study included 70 participants, predominantly female (77.1%), with a sex ratio (M/F) of 0.30. The mean age was 35.77 years (range: 24–49), with most participants (61.4%) aged between 31 and 37. Regarding professional experience, 47.1% had worked for 5 to 7 years, and 32.9% for 1 to 4 years. Dermatology was the most represented department (30%), followed by nephrology (24.3%) and internal medicine (21.4%). Most nurses (64.3%) were from Farhat Hached University Hospital, while 35.7% worked at Sahloul University Hospital.

Most participants (92.9%) recognized lupus as an autoimmune disease, though few identified it as chronic. Over 60% cited women of childbearing age as most affected (Figure 1), and 45.7% named stress as a key trigger. Immunosuppressants (77.1%) and corticosteroids (68.6%) were the best-known treatments. Nearly half misidentified the role of immunosuppressants, while toxicity and infections were the most reported side effects. Preventive measures were largely unknown (87.1%), with sun protection, nutrition, and infection monitoring cited by a minority (Table 1). Nearly 47.1% saw nurses as key in communication, care coordination, and psychological support. Therapeutic education (32.9%) and stress management (37.1%) were the most cited strategies for managing lupus flares. Nearly half of the respondents (47.1%) believed that nurses should play a multifaceted role in the care of patients with lupus, encompassing communication, care coordination, and psychological support. Approximately one-third (32.9%) identified therapeutic education as the primary strategy to help patients manage disease flares, followed by stress management strategies, which were mentioned by 37.1% of participants when similar responses were grouped. More than half of the participants (52.9%) considered attending conferences on autoimmune diseases as the most effective way to stay updated on the latest clinical guidelines. However, a large majority (74.3%) reported not having received any specific training on lupus during their nursing education.

Table 1. Nurses' Accuracy on Prevention Measures Associated with Treatments

Prevention Measure	Frequency	Observation Percentage (%)
Proper diet (salt reduction)	4	44.4
Sun protection (sunscreen + reduced exposure)	3	33.3
Infection monitoring and prevention	2	22.2
Total	9	100

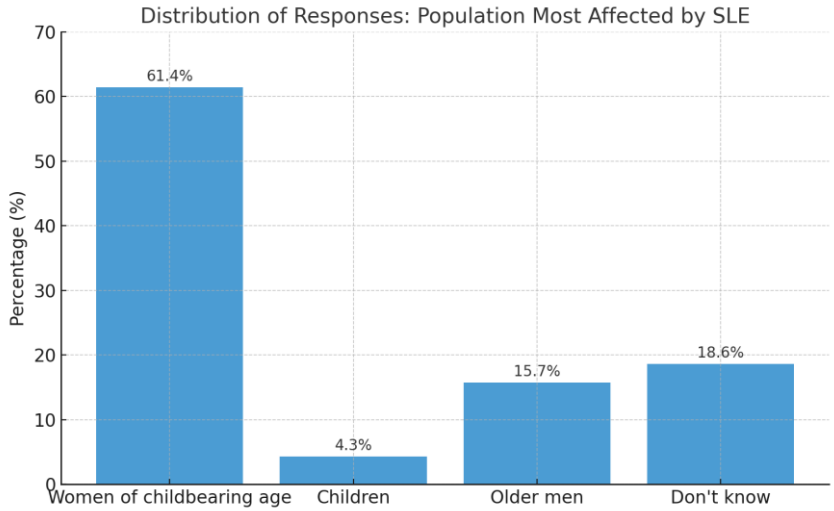

Figure 1. Distribution of Responses on the Population Most Affected by SLE

4. Discussion

In our study, the female predominance among nurses (77.1%) reflects the historically feminized nursing profession in Tunisia (male-to-female ratio 0.30). The average age (35.8 years) indicates a mid-career workforce, with nearly half having 5 to 7 years of experience, a key period for clinical skill development (Karp I & Chan J., 2013; Fanouriakis A, Kostopoulou M, Alunno A, et al., 2019). Dermatology, nephrology, and internal medicine—specialties frequently managing systemic lupus erythematosus (SLE)—were the most represented departments (Ben Said A, Ferjani A, Mhiri A, et al., 2020; International Council of Nurses, 2021), with most participants from Farhat Hached University Hospital, a major training center (Naifar M, Chebbi F & Bouguerra A., 2019). While 92.9% correctly identified SLE as an autoimmune disease, only 12.9% recognized its chronic nature, and 20% confused it with an infection, common misconceptions that may hinder care (Bouzidi S, Mebarki F & Ait Salah M., 2020). Classic symptoms such as rash, fatigue, and joint pain were well recognized, whereas less specific signs like weight loss were underappreciated, limiting early detection. Nearly 60% considered SLE rare, although it primarily affects women of childbearing age. Stress was identified as a trigger by 45.7%, and 71.4% understood the multisystemic nature of SLE (Hahn BH., 1998). Antinuclear antibodies (ANA) were identified by 85.7% as the key diagnostic test (SLEuro, 2023), though 12.9% were unaware of specific tests. Therapeutic knowledge was adequate for immunosuppressants and corticosteroids, despite confusion regarding their use during infections and their side effects (SLEuro, 2023). Cyclophosphamide was the most cited treatment for severe cases (81.4%), whereas newer targeted therapies like belimumab were less recognized (Centers for Disease Control and Prevention, 2024). Notably, 87.1% were unaware of preventive measures linked to treatment, critical for long-term care. Nurses recognized their educational and evaluative roles, with 77.1% assessing family history, a key genetic factor (Healthline, 2023). Blood pressure monitoring (15.7%) and corticosteroid administration (4.3%) were rarely mentioned despite their importance (Aringer M, Costenbader K, Daikh D, Brinks R, Mosca M, Ramsey-Goldman R, et al., 2019). Sun protection was advised by 48.6%, though 11.4% were unsure, revealing knowledge gaps needing targeted education. Hydration, diet, relaxation, and peer support were widely endorsed to improve quality of life and adherence. Only 14.3% discouraged physical activity despite evidence supporting its benefits (Petri M, Orbai AM, Alarcón GS, Gordon C, Merrill JT, Fortin PR, et al., 2012). Regular follow-ups (70.6%) and symptom management (61.8%) were well recognized, but physical activity promotion was insufficient (Chahid N, Ait Benali S, El Mansouri I, et al., 2021). Nearly half saw their role as multifaceted, including communication, care coordination, and psychological support. Therapeutic education (34.3%) and stress management (37.1%) were common, while infection prevention and sun protection were less cited. Over half preferred attending autoimmune disease conferences for updates, with only 12.9% citing online training despite its accessibility and institutional endorsement (Hahn BH, McMahon MA, Wilkinson A, Wallace WD, Daikh DI, Fitzgerald JD, et al., 2012). A significant 74.3% of nurses lacked specific lupus training during their initial education, contributing to gaps in patient care. Nurses with specialized lupus training better recognize symptoms and manage complications. Thus, including autoimmune disease modules in nursing curricula is essential. Additionally, 51.4% rated their knowledge as average and 31.4% as low or very low, a self-assessment associated with suboptimal care and communication (Chambers SA, Allen E, Rahman A & Isenberg DA., 2009). Ongoing training is crucial to enhance lupus care quality and patient support.

Systemic lupus erythematosus (SLE) is a complex, chronic autoimmune disease posing significant challenges for healthcare providers. Nurses play a crucial role in early detection, therapeutic education, follow-up, and psychological support. Our study reveals concerning gaps in nurses' knowledge and confidence, particularly in autoimmune pathophysiology, treatment management, and patient education. These deficiencies risk compromising care quality and patient outcomes. Addressing these issues requires targeted continuing education, integration of autoimmune disease modules in nursing curricula, and use of interactive training methods. Ultimately, empowering nurses with comprehensive skills and empathy is essential to improve SLE patient care and quality of life. This work highlights the urgent need for enhanced nurse training to meet the specific demands of SLE management.

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